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ORIGINAL ARTICLE

A qualitative study exploring the lived experience of medication use in different disease states: Linking experiences of disease symptoms to medication adherence

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Abstract

What is known: Medication non-adherence leads to negative health outcomes. Medication adherence is predicted if patients understand the necessity of medication use to control disease symptoms and progression. It could be expected then, that patients with diseases with symptoms which are managed with medications, such as chronic obstructive pulmonary disorder or gout, or diseases with high-mortality rates, such as cancer, would have higher adherence rates than asymptomatic diseases, such as hypertension. However, poor medication adherence remains problematic in both symptomatic and asymptomatic diseases. Further work is needed to explore patient experiences of medication adherence to understand the link between adherence and symptom control.

Objective: To explore patients' lived experiences of medication adherence.

Methods: Participants were recruited from community pharmacies and general practices. Forty-one semi-structured interviews and three focus groups were used to collect data from patients with disease states that had different symptomatic and asymptomatic profiles. Inductive thematic analysis was used to identify key parts of the experience of using medications.

Results: Participants reported similar experiences of medication adherence despite having different disease symptoms. Participants said that they used medications because it was an expected part of everyday life and that medications 'must be needed' because they had been supplied, rather than being used for a particular symptom. Participants reported short-term episodes of non-adherence were unlikely to lead to negative health outcomes but may result in negative social consequences.

Discussion: The findings broaden our understanding of patient experiences of medication use by indicating patients with symptomatic and asymptomatic diseases share similar experiences of medication use. The necessity to use medications appeared to come from 'the system' of healthcare professionals, family and friends that supply and recommend medications.

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What is new: There were key similarities in experiences of medication adherence in patients with different disease states. The negative consequences of short-term episodes of non-adherence were normalized by healthcare professionals.

Conclusion: Patients with symptomatic and asymptomatic diseases share similar experiences of medication adherence.

KEYWORDS

clinical pharmacy, medication adherence, medicine use, qualitative research, symptom control, treatment strategies

1 | WHAT IS KNOWN

Understanding patients' experiences of medication use is important as non-adherence to medication for long-term conditions leads to increased morbidity and mortality.¹⁻³ For example, poor adherence (defined as taking less than 80% of prescribed doses) to anti-hypertensives and statins is associated with approximately 9% of all cardiovascular events in Europe.⁴ The literature presents different ways of understanding medication use using biomedical, psychological and socioeconomic paradigms.⁵ For example, medication use has been understood using different classifications, such as intentional and unintentional non-adherence, or within stages of treatment such as initiation, implementation and discontinuation.⁶⁻¹¹ Qualitative research suggests medication adherence is associated with psychological and sociological factors; such as distrust of medication,⁹ the influence of medications on interactions with other people,^{12,13} knowledge about the necessity of the medication and fear of side effects (the Necessity Concerns Framework),^{14,15} and self-efficacy.¹⁶ Other evidence suggests interactions with healthcare professionals during the supply of medication gives medication use 'special meaning', which influences patients to use medications as prescribed.¹⁷ Despite a wide variety of ways of understanding this phenomenon, medication adherence remains problematic.

The NCF has obtained wide-spread acceptance and is pervasive both within the academic literature as well as professional practice.^{8,18-20} Although historically focused on both the necessity to use the medication and concerns regarding side effects of using medication, a meta-analysis of published literature showed that patients' experiences of medication adherence are framed by 'the necessity' to control symptoms, more than concerns about side effects.¹⁴ The NCF has also translated into the patient sphere, where medications are expected to be used when necessary for symptom control.²¹ The relationship between adherence, symptoms and the need for increased healthcare intervention is well evidenced. For example, in respiratory diseases, poor adherence increases hospitalizations and morbidity due to an increase in symptoms during exacerbations.²² The necessity to take the medication as prescribed to control symptoms and avoid hospitalization may appear obvious to both patients, who are experiencing symptoms, and healthcare professionals supporting patients to manage their symptoms. The NCF has provided

theory for the development of national and international guidelines, as well as interventions to optimize medication adherence.^{14,23}

2 | OBJECTIVE

As explained by the NCF, the efficacy of a medication to control symptoms, such as pain and breathlessness, is thought to motivate patients to adhere to medication,^{13,15,16,24} and represents 'the necessity' to use medication as prescribed. This could mean that for diseases that are symptomatic, like respiratory diseases, higher rates of medication adherence may be expected than diseases that are asymptomatic, like hypertension. However, approximately 50% of all medications are not used as intended, in both symptomatic diseases, such as chronic obstructive pulmonary disease and gout, and asymptomatic diseases, such as cardiovascular and metabolic disease.²⁵ Even in conditions that have acute and life-limiting symptoms, such as cancer, medication adherence remains problematic.^{12,15,26,27} This suggests, 'the necessity' to use medication may not be underpinned by a desire for symptom control and may be based on other experiences.²⁸ However, there is limited empirical evidence directly exploring and comparing experiences of medication adherence in patients with different symptoms of disease, simultaneously. Therefore, the aim of this study was to explore the lived experience of medication adherence in patients with symptomatic and asymptomatic diseases.

3 | METHODS

This paper uses the consolidated 'criteria for reporting qualitative research' (COREQ).²⁹ Ethical approval was awarded for this study by an NHS Ethics Committee (Ref 14/SC/0272) and the Research Ethics Committee of the School of Medicine, Pharmacy and Health, Durham University (Ref ESC2/2014/3).

3.1 | Study design and setting

This research adopted a phenomenological approach.³⁰ This qualitative methodology is used to understand the essential components of phenomena and transcend previous presuppositions.^{31,32}



This design was chosen as it enabled researchers to set aside a priori knowledge via 'bracketing' and explore phenomenon in a new way to reduce bias from existing presuppositions. Grounded theory, case study, narrative approach, phenomenology and ethnography are reputable and rigorous methods that could be used to study patients' real-world experiences of adherence. Deciding which qualitative research approach to use can be difficult. Differing philosophical, conceptual or theoretical frameworks or ideologies can underpin each approach.³³ Aligning the aim of the research with the underpinning ontological, epistemological and theoretical perspective of the chosen methodology allows a theoretically congruent research approach to be adopted.³³ Medication adherence can be defined and described using a plethora of conflicting conceptual or theoretical frameworks and so aligning to one of these presented somewhat of a challenge, as epistemologically it meant giving predominance to one 'way of thinking' about adherence.⁵

We felt a narrative approach may subjectively reconstruct the phenomenon, potentially devaluing or over valuing our awareness of the chemical nature of medicines and missing the reality of using medications that exist in patients' experiences. An ethnography, which includes observation of culture-sharing groups, was not considered appropriate as just because two people share an experience of illness does not infer they share a culture. Ethnography would also require a substantial amount of time in the field, using observations, which was not practically possible for the research team. Grounded theory attempts to produce a novel theory, interpreting the experience of the phenomenon to generate an explanatory model.³³ As a number of explanatory models already existed, such as the NCF, we felt that this would not 'fill a gap' in the literature. Phenomenology, however, rejects presuppositions and prejudices about a phenomenon through a process known as epoché and seeks to produce a novel description of experience that helps a phenomenon be seen in a new way.³⁰ We felt that as pharmacists and a medical sociologist, this was a preferred methodology as it helped us identify our previously held beliefs about adherence and try to find a new way of thinking about adherence that captures the reality of patients' experiences.

Previous research methods were used to collect large amounts of rich data and give direct access to patients' lived experiences, perceptions and beliefs.³⁰ Semi-structured, one-to-one interviews ($n = 41$) were conducted at the participants' convenience in their homes or at the University. One participant requested his wife was present for the interview; however, the remaining interviews were conducted with only the researcher and the participant present.

Three focus groups were also conducted, two at the University ($n = 7$ and $n = 6$ respectively) and a third focus group at a community centre ($n = 3$). A member of the research team conducted the focus groups and was supported by other PhD students and post-doctoral researchers. Focus groups and interviews were used as two methods of data collection (one-to-one and in a group) to expand and validate the study findings.^{32,34}

3.2 | Participants and recruitment

Participant recruitment took place in the United Kingdom between June 2014 and June 2015. Participants were invited to take part by four general practitioners (GPs) and four community pharmacists (CPs). GPs and CPs were selected across a range of deprivation indices using the Index of Multiple Deprivation Score (IMDS)³⁵ to include patient experiences from different socioeconomic settings. The IMDS scores areas based on income, employment, education, health, crime, barriers to housing and living environment.

Participants were invited to participate by GPs and CPs using a purposive recruitment strategy with the following inclusion criteria: adults (≥ 18 years old); with capacity to give consent; who were conversant in English; willing to speak about their experiences of medication use and prescribed medication for diabetes, chronic obstructive pulmonary disorder, cancer, gout or cardiovascular disease in the last six months. These five disease states were chosen to provide a range of experiences of high- and low-acuity illnesses with different symptomatic profiles, to explore similarities and differences between disease states, symptom control and adherence. GPs and CPs screened their existing health records for patients that matched the inclusion criteria, contacted these patients directly and obtained consent for patient contact details to be shared with the research team. Once contact details had been shared with the research team, we contacted patients to coordinate their participation in the study. GPs and CPs also displayed posters that said 'Have you had [disease state]? We are trying to find out about patient experiences of treatment. Ask your [GP/CP] for more information'. Patients that expressed an interest were given a Participant Information Pack (which included information about the study, the research team, how to take part in the study and a consent form). Participants then contacted the research team to coordinate their participation in the study. The number of people invited to the study that refused to participate was not recorded to prevent task overburdening of community pharmacists and general practitioners. Following the recruitment and completion of interviews, GPs and CPs were asked to use the same strategy to recruit additional participants to take part in focus groups to validate findings.

Data saturation is reported in the literature at between 6-15 participants.^{30,33,36} The research team planned to recruit a minimum of 6 participants and up to a maximum of 15 participants for each disease state, so that saturation could be reached for each disease state sub-group without producing overwhelming amounts of data. This equates to a minimum of 30 participants and a maximum of 75 participants so the research team planned to recruit between 45 and 55 participants.

3.3 | Data collection

Demographic data relating to age, gender, occupation, post-code (to identify level of deprivation) and comorbidity status were collected for each participant and is summarized in Table 1. Interview

TABLE 1 Summary of participant demographics

Description	n=	%
Participation	57	100%
Interviews	41	72%
Focus group	16	28%
Gender		
Male	34	60%
Female	23	40%
Age		
≥80 years	7	12%
70-79 years	20	35%
60-69 years	17	30%
50-59 years	11	19%
35-49 years	2	4%
Level of deprivation		
High	22	39%
Intermediate	11	19%
Low	24	42%
Occupation		
Retired	33	58%
Working	17	30%
Unemployed	7	12%
Disease state		
Cardiovascular disease	20	35%
COPD	10	18%
Gout	8	14%
Cancer	8	14%
Diabetes	11	19%
Co-morbidity		
Yes	32	56%
No	25	44%

Note: The data indicate that the sample for the study were mostly males, who were retired. Participants with cardiovascular disease were over-recruited compared to other disease groups. There was a good spread of participants from areas of high, intermediate and low deprivation. The majority of people in this study were over 60 years old.

and focus group topic guides were developed and piloted with a patient and public involvement (PPI) group (see Supplementary information). The questions were adjusted based on feedback from the PPI group so that the questions did not make it obvious the research was about using medication to control symptoms. During interviews and focus groups, participants were asked three open-ended questions about using medications that enabled them to tell their stories of using medication in their own way – rather than being led by the interviewer to link their disease or symptoms to medication use. The questions were (a) 'what happened when you were diagnosed?' (b) 'what are your experiences of taking your medicines as prescribed?' (c) 'what are your experiences of not taking your medicine as prescribed?' Probing questions were used to explore how medication use related to experiences of diagnosis, symptoms and everyday life

but varied between participants depending on how participants responded to questions. Interviews were audio-recorded, transcribed verbatim and quality checked. We checked interview transcript quality by listening to the audio-recording of the interview and reading the transcript simultaneously for a random 10% sample of interview transcripts. This enables common errors to be identified and can prompt further checks on the transcripts if major errors are identified. Only minor errors were identified in this sample and these were rectified by the research team.

Data saturation, *that is*, the point at which data sounds familiar with the same experiences appearing over and over again and different data do not emerge, was reached at different points for different disease states.^{33,36} Participants that had been invited to the study were still interviewed after saturation had been reached, to respect their commitment to the study. Following the completion of the interviews, three focus groups were conducted to explore, expand and validate the study findings.^{32,34} The focus group included a brief overview of the results of the study so far and then turned to participants to explore their experiences of medication use, using the same topic guide as the interviews to prompt discussion. Focus groups were audio-recorded, transcribed verbatim and quality checked. Interview and focus group transcripts were not returned to participants for comment or correction.

3.4 | Data management and analysis

Inductive thematic analysis was conducted after each interview and focus group as well as after all data collection was complete.^{30,33} Transcripts were read line-by-line whilst listening to the corresponding audio-recording to create codes. Codes were generated, deconstructed and merged until clusters (similar codes) and dominant themes emerged. We used a descriptive coding technique,³⁷ which included the following steps (a) familiarization with the data by re-reading transcripts, (b) ascribing descriptive codes to sections of text by summarizing it in a word or noun to identify textural and structural data (c) coding phrases inductively, clarifying meaning by comparison to other codes within the data set (d) clustering codes together to identify common ideas, meaning, emotions and theory, (e) transforming codes into relevant and understandable themes, by combining clusters and reflecting to ensure the meaning of the code is not lost. All members of the research team contributed to analysis using manual coding and NVivo12. Thematic analysis, underpinned by phenomenology, was used as it enabled analysis to go beyond the content of interviews, identifying relationships between key parts of participant experiences.^{30,33,37} Phenomenology requires researchers to *epoché* or 'bracket' prior to analysis to identify prejudices, biases and a priori knowledge.³⁰ Bracketing helped the team critique their analysis against identified prejudices and adds rigour to the analysis, as it forces researchers to interrogate codes and themes to ensure the analysis is inductive and based on data, rather than previously held beliefs. We bracketed by holding regular meetings to explore past



and present beliefs relating to medication adherence, pharmacists, patients, different disease states and other concepts with trusted colleagues within and external to our School.³⁸ Memos were also made during the analysis which were discussed during meeting and reflected upon.³⁸

Rigour was also added throughout the analysis as preliminary findings were presented at research group meetings with academic pharmacists and qualitative researchers, who helped scrutinize the coding. Using computer coding also added rigour to the analysis as it established a date-tracked audit-trail, enabling researchers to reflect on how codes and themes were constructed over time and by whom.³³ Participants and a PPI group also provided feedback on the findings at a research engagement event, which further validated the findings.

Data from focus groups were analysed using the same approach as the interviews. Findings from the focus group data were compared and contrasted with findings from interview data to validate interview findings.

3.5 | Research team and reflexivity

The research team included three clinical pharmacists (APR, AT and AKH) and a medical sociologist (KJ). The research team and participants did not have a relationship prior to the study. Participants were informed that the interviewer was a doctoral student and a pharmacist, but that no clinical advice could be given during the interview, no information would be passed to their usual care team about non-adherence and that we were looking for open and honest accounts of experiences of using and not using medications as prescribed. This was done to reduce the chance of bias that participants would only share 'positive' or pro-social experiences of using medications.³⁹ The management of the professional ethical and legal tensions this created are reported in detail in another paper.⁴⁰

4 | RESULTS

Forty-one participants took part in one-to-one interviews. Interviews lasted between 67 min and 46 s and 115 min and 29 s, with a mean interview length of 90 min 12 s. Sixteen participants took part in focus groups. Focus groups lasted between 87 min 57 s and 112 min 23 s. Focus Group 1 had seven participants, Focus Group 2 had six participants and Focus Group 3 had three participants. We appreciate Focus Group 3 is a very small group; however, we still wanted to include the data from this group as they were quite a vibrant group and although not ideal in terms of numbers of participants, it did work well. Demographic details of participants are summarized in Table 1 for further information. Data was synthesized and findings of the analysis are presented below.

Three themes were identified that represent key components of the experience of medication adherence in each of the different

disease groups. These were (a) identification, (b) necessification and (c) routinization and adaption.

4.1 | Theme 1) Identification

Participants described experiences of 'getting to know' their medications through a process of identification.

well you have to get to know your medicines initially, because when they first give you them, you have no idea what they are or what they're for. I mean obviously you know what they are, they're medicines and they're for something, but really it's just like you know they exist and people take them when they're told to, but you don't actually know the individual ones you're getting, then gradually you start to get to know them then in the end you know them quite well really, they're a part of your life. -

P8, cardiovascular disease

The identity of medications was based on experiences of the action of medications as physical sensations in the body which confirmed that expectations of the participants to use medication had been fulfilled.

over time you get to know them really well, because they do things to you, so for example that one [holds up salbutamol] I know is really good, because when I take it, I can feel it settling on my tongue, so I know it's definitely gone in and that sort of calms me down, because I know I'm doing what she [the carer] wants and what the doctors wants and it just feels right. And that feeling doesn't go away, I mean now when I use it, to be honest I can't tell if it's going in or not, but it feels like I'm doing what I should be doing, I'm doing my bit, so to speak because its doing its bit -

P32, chronic obstructive pulmonary disease

In the extract below, the participants' expectations of the action of medications were based on prejudices about the physical characteristics of the medication, for example, the size and shape, where small dosage forms were thought to be less harmful, and information from healthcare professionals and friends.

The ones they gave me were only very, very small, and even though the doctor was saying they're very good, I'd heard from a friend they were actually quite nasty, not very kind to your stomach, so I was a bit unsure about what they were really like at first, but then once I'd taken them, they did upset my tummy so I knew they were going in, but I felt that sense of relief that, you know, things will get better now, and because they were only small things, you know even

though they are a bit nasty, they're only small so what harm can they really do?-

P1, gout

Medications that created physical sensations that were expected, that is, side effects, had characteristics such as 'strength' and 'good workers'.

it's quite an important characteristic of my medications, that you know, they do do something, because I know they're doing it because of the side effects, so my [medication] makes my tummy go queasy. So, although my symptoms are still there, and to be honest, I'm not sure the medication knows where the problem is, because the medication's working on my stomach, so if it's doing something there, who am I to say it's not doing something somewhere else? I mean I can still feel the problem I went in for, it's still there, the symptoms are still there, but if you get told to take it and then you can feel it doing something, even if you don't understand what it's doing really or you think it's doing something in the wrong place, you're going to keep taking it because it is doing something, I mean just like you would expect it to because that's what people say isn't it, you take the medication because it needs to work in your body. So, you know that that medication, itself, is a good worker, it's got enough oomph [strength] to do something, it's behaving as it should so I take it as I should

P29, diabetes

The experience of physical effects and abstract characteristics that participants heard about medications created the identity of the medication, as having 'oomph' interpreted in the extract above as strength, which re-assured medications were 'behaving' as expected. If medications 'behaved' as expected (i.e., caused a physical sensation) participants responded by 'behaving' as they were expected to, using medication as prescribed.

This was reinforced when medications did not 'behave' as expected, that is, did not cause physical effects, and made the participant feel as if they had not taken anything.

The medications they give me initially didn't really do anything so I wasn't taking them, I mean, they might have done something, but I didn't feel like they were. I mean I got the impression from the people that gave me them that it was a bit pointless taking them to be honest, and other people with cancer I'd spoken to had said they didn't feel anything when they took it. But I thought, I'll give this a go, it might work for me, but then to be honest with you, I think I took a handful, but nothing happened. So if you've been given a medication, and you identify that it's a bit of a dud

one, that doesn't really work, it makes you feel like, like you shouldn't put the work in to take it, if it's not going to do the work once you've taken it. So, I didn't bother with the rest after that. At the end of the day, I still had cancer and if I couldn't feel them doing anything what was the point? -

P35, cancer

Participants that could not feel the physical effects of the medication, identified these medications as weak or not working and were not motivated to take medications as prescribed.

4.2 | Theme 2) Necessification

Participants reported getting to know their medications over time; however, the 'need' to use medications was inherent in being supplied a medication.

If I was given a medicine then I'd have taken it, because that's just what you do isn't it, you're given a medication for a reason, so you take it -

P41, cancer

The reason medications were needed could vary from the prescribed indication; for example, one participant was prescribed co-codamol for pain relief but used them nightly as an anxiolytic.

I take [...] two co-codamol [...] they are my little friends on a night-time, I need to take them because on a night it relaxes me,

P24, chronic obstructive pulmonary disease

Using medications as they were prescribed was described as a necessity to deal with everyday 21st century life.

I mean using medicines now, in the 21st century, it's just part and parcel of life isn't it? Even from being a young 'un you need to use stuff, because they help don't they? I mean even now my grandkids they're taking medications every day, because it keeps them going you know. The world is tougher than it used to be now, you know people working the weekends, in the night, always attached to a screen, so the wear and tear of everyday life, that needs to be smoothed out with a pill. And even you know, the kids when they go clubbing, they take pills don't they? I mean they're probably not meant to, but they take pills the next day to deal with the hang over don't they? So really, for me, when I was told I was going to have to take a medication, I just felt like, yeah okay, this is normal. It wasn't a big deal or anything. -

P6, diabetes



Other participants described feeling that they had no choice but to 'take medication' and although this was an expected part of everyday life, it was needed to maintain survival. One participant simplified his interaction with pharmaceutical products as binary, life or death.

if you want to live, you've got to take them...[...]the box is there, I know it's there and I know I have to take them, it's either take them or die, simple as that isn't it?

P18, chronic obstructive pulmonary disease

That using medications was experienced as a key part of survival, not using medication as prescribed was considered selfish because of the social implications poor health and death may have on people around them.

for somebody that is of a reasonable age who doesn't want to take tablets to help them have a normal a life as possible with the aid of tablet, I just don't see any reason why they're just not going to do it. [...] especially if they're of an age where people are dependent on you, like if you're the husband and you're married with a wife and kids and what have you, these people don't deserve to be left on their own with me being selfish

P26, diabetes

The majority of participants conceptualized the necessity of medication adherence as a function of their survival in relation to their social life.

I don't think they give you these tablets unless you need them... and if you stop taking them then you're putting your life back at risk, therefore if anything happens then you're putting your life back in risk, it's the individual person that then has to deal with the consequences of that on their family or friends or pets or whatever. It's up to them, you can't twist their arms and put it down their throats, but I don't think they would give you them if you didn't need them

P7, cardiovascular disease

This suggests that despite variation in symptoms, morbidity and mortality between participants with different diseases, the shared a necessity to use medications which came from medications being supplied.

you must need to take them, otherwise why would they give you them? I mean I don't know what it's doing inside me or why I need it really, but if I didn't need it they wouldn't give it to me would they? They

only give you them cause you need them and to have to take them,

P22, gout

Being told medications were needed by 'the system' meant participants used medication, even if they didn't really want to.

I wouldn't say you come resigned [sic] but you just come to taking the tablets even if you don't really want to, because the whole system is telling you you need to take them, you get letters, you get texts to pick them up, you see people on the telly taking their medications and that makes you think oh I need to remember to take mine as well

P26, diabetes

However, participants reported changing their views about the necessity of taking medications as prescribed, based on the reaction of healthcare professionals.

Well in the beginning I would worry about not taking them, like if I missed one or ran out or there were people around us if we were on holiday and I couldn't take it front of them, I used to panic a bit about it but one time I'd forgotten for a couple of days, maybe three or four days, and I went to the pharmacist and they said that actually, it's not a problem, just carry on taking it. And he was so blasé about it that it made me think well they can't be doing that much good can they? So now if I miss them, I don't worry. I suppose if I said to him I want to come off them permanently, he'd be a bit more bothered, because then he'd lose a customer, but in all seriousness I don't worry about not taking them over a couple of days. If it was long-term, then I think I do need them, because obviously the NHS is paying for it for a reason isn't it, but really, in the short term, here and now, I'm not really sure why I need to take them, but I do.

P17, cardiovascular disease

One participant reported he no longer felt any medications were needed because 'they' (the doctors and nurses) in the system, changed his therapy which made him doubt the need to take any medications at all.

to tell you the truth, it doesn't make you feel any different if you take it or you don't, you still have diabetes either way so I don't see the point in taking it all the time. But then when she said she wanted to stop the injections and put me on something else, otherwise I'd end up dead, and I just thought hold on, you've told me before it's fine and now you're saying I'm going to die? It just makes you doubt what they're

all saying to you, the nurses and the doctors, if they can stop, and swap, and change your medicines all the time, do you really need them in the first place? So, I talked about it with the wife and together we decided just to stop them, because it's no fun really.

P02, diabetes

The participants in this study experienced a shared necessity of using medications despite differences in their disease symptoms. The necessity to use medication for these participants was inherent in the products that were supplied. The system (doctors, nurses, pharmacists, friends and family) made participants feel that their medication was inherently needed; however, dissonance in the system meant the necessity of using medications could be lost, and resulted in experiences of non-adherence.

4.3 | Theme 3) Routinization and adaption

Over time the necessity and identity of medications appeared to become a secondary part of the experience of medication use, replaced with routine and automated interactions between the patient and the product.

The regular use of medication was present in participants with chronic, asymptomatic diseases such as cardiovascular disease.

well I take them at night, every night, that's my habit, my routine. It's like getting ready for bed on a night, having supper and things like that, you do it the same every day, like brushing your teeth, it just part of the habit you get in to, It's not like I take it for a particular reason, you know I don't think oh I'm feeling unwell I better take my medication, I just take it routinely come rain or shine, because that's what you're supposed to do

P7, cardiovascular disease

This meant medication use became habitual.

I didn't want to take them at the beginning, but with reluctance it was just habit forming. I had to get into the habit of taking them and once I'd done that, I had no problem taking them, it was just automatic, second nature

P3, diabetes

The routine use of medications was also experienced by participants with acute, symptomatic illnesses.

I don't see it as a problem, I mean lots of people like routine anyway don't they? If they get into it then you just do it

P5, gout

Participants with significant and potentially life-limiting illnesses, such as cancer, have similar experiences of routinely using medications.

I think you just get into the routine and then it becomes second nature to you to be truthful

P40, cancer

Physical experiences of the action of the medication that helped participants initially identify if the medication was working became secondary once habitual medication use was established. Rather than focusing on what medications did physically, participants reported trusting that the medication was 'doing what it was supposed to'.

It doesn't really bother me, I just take them you know, a habit, put it that way, a habit you just automatically take them and hope that they're going to do their work, I can't say that I'm that keen on taking them and I don't really know what they're doing inside me, I don't feel them doing anything so much anymore, but I carry on taking them anyway because it's part of my routine now

P20, gout

These data suggest that routine becomes an important part of medication adherence once participants had 'got to know' their medication worked, even if they could no longer feel the medication working. Although the necessity to use medications was still inherent because medications were supplied, one participant described he felt his need to take medications was reinforced as using medications became a part of life.

I need to take them because it's part of my routine, if I didn't have to get up to take them, I probably wouldn't get up I don't think. It, in a way, in the beginning, you take them because someone gives them to you and so you feel like it must be something you've got to do, you know, to survive as it were, but then after a while, it doesn't feel like they're keeping your alive so much as using them is part of life, so if you didn't have to go to the doctor, get the prescription, pick it up, count them out, put them in the box, go for the blood tests, forget to take them, remember to take them, have the side effects and all that, that actually life itself would be quite different, so they keep you alive but they also give you a life, because if it wasn't for all the work and people involved in getting them, I don't think I'd speak to a soul, I don't think I'd have very much of a life at all. It keeps you active, I mean, I'm not very old and I've never really worked, but I think it's a bit like work, keeping yourself in the routine to take your medication -

P12, cardiovascular disease



However, other participants described an alternative view that included episodes of short-term non-adherence within their medication-taking routines. For example, missing one or two doses or 'a few days' worth of medication was not perceived negatively and had little impact on short-term or long-term symptoms or survival.

oh yeah, but what I don't do, I won't take them if I'm missed them in the morning I won't take them late on of an evening if I'm going to have to take them of a night-time, because that, in effect, on some of them is doubling them up – if I've survived that long [without them], I'll survive another couple of hours [laughing]-

P3, diabetes

Participants reported adapting their medication use routine to accommodate missed doses, by minimizing the detrimental effects of non-adherence.

I did panic a little bit and I don't know why I should, but you know you think, is it going to make any difference if I miss one? Well you know it's not really, [...] as time passes, you get to be a little bit more, 'calm yourself down a little bit, missing one tablet isn't going to make any difference' [laughing] I did worry at the beginning you know, if it would have any effect on me if I did forget but I'd only forgotten for about six hours so really, you know, it's a bit silly you know, looking back on it now you know, 'get a grip' [laughing]

P36, cancer

Adaptations to medication routines appeared to be influenced by social life (e.g., interactions with other people).

I've got somebody round and we're talking, the [reminder] goes off and I think 'oh tablets' I'll remember that but of course they're there for another hour maybe, I'm still talking, and when [the person] goes I haven't thought anymore about the tablets so the alarm is pointless [laughing] yeah, I do [miss them], I wouldn't say I do it often, but I've certainly done it several times -

P9, cardiovascular disease

However, patients described that beyond a few hours or a few days, non-adherence may become socially problematic.

to be honest with you, it doesn't make a bit of difference if I miss a couple of doses, you know, I mean, I know I've missed them or I'll work out I've missed them, but as long as the missus doesn't find out, it's not a problem. It's not like it has an effect really if I only miss a couple, I think more than that, like if I just

stopped taking it, I think the missus would be after [laughing] -

P32, chronic obstructive pulmonary disease

This suggests that patients' experiences of medication adherence, including short-term missed doses, are focused on social consequences rather than symptomatic ones. This establishes routine non-adherence as a constitutive part of patients' experience of medication adherence.

5 | DISCUSSION

Participants described experiences of identifying or 'getting to know' their medications based on the action of the medication on their bodies; on unique physical characteristics of the products (e.g., colour, size, shape) and on abstracted, subjective attributes, such as kindness and nastiness. Using medications was an expected part of life in the 21st century. The necessity to use medications came from 'the system' – doctors, pharmacists, friends and family, that supplied, recommended or expected medications to be used as prescribed. Over time, participants established routine medication-taking practices, which reinforced the necessity to use medications as part of everyday life, to give life structure. Routines included short-term episodes of non-adherence with consequences that were social, rather than health outcome related. The findings indicate that participants with different disease symptoms shared key parts of the experience of using medications based on the physical effect of the medication on their bodies and the social effects of medication use on the people and healthcare professionals around them.

These findings provide evidence that adherence is experienced similarly in patients with different diseases and is a phenomenon of necessity.^{14,23,41} This presents additional support for work that argues necessity, rather than being based on symptom control or disease progression, is inherent in the medications themselves when they are supplied by health professionals.¹⁷ This adds further to existing work which suggests the social status of pharmacists (and other healthcare professionals) may be central to the necessity of a medication, transferring 'special social meaning' to using medications during the supply process.¹⁷ However, participants in this study experienced medication non-adherence when there was dissonance with information from healthcare professionals in 'the system'. This suggests that in addition to repeated exposure to healthcare professionals, the consistency of information provided to patients by healthcare professionals may be an important part of medication adherence. The development of interventions that lead to sustained improvements in medication adherence may need to focus on repeated and consistent exposure to healthcare professionals within 'the system' that supplies medications, to identify ways to ensure that medication use retains its 'special meaning'.

Our findings support existing qualitative research which describes adherence as a function of relationships between people.^{9,12,17} The 'special meaning' ascribed to medication from healthcare professionals involved in supplying them may also come

from others – such as family, friends, newspapers and the internet. In participants in this study, the social basis of adherence appeared to be more important than the health consequences of non-adherence. This suggests exposure to information about medication use may not necessarily need to relate to health consequences, but rather could relate to social norms, trends or impact. Further work is needed to explore patients' experiences of adherence in relation to exposure to information about medication use and how this informs patterns of adherence or non-adherence.

6 | WHAT IS NEW

There were key similarities in experiences of medication adherence in patients with different disease states. The routinization of missed doses by participants in this study is concerning. For healthcare professionals and policy makers, the therapeutic and socioeconomic consequences of medication non-adherence are problematic.^{17,32,35} Non-adherence increases rates of mortality in multiple disease states.^{2,3,22} Yet the participants in this study shared the experience that non-adherence was not problematic and would not have negative health outcomes. There is limited evidence of the minimum level of adherence to achieve therapeutic outcomes. However, the normalization of medication non-adherence could lead to lower drug serum concentrations, contributing to poorer health outcomes.⁴² In this study, participants reported not observing the physical effects of missed doses contributed to the normalization of non-adherence. Additionally, participants in this study reported the minimization of short-term non-adherence meant non-adherence could become routine. Health professionals should therefore try hard not to minimize non-adherence and to link non-adherence to missed therapeutic outcomes; utilizing drug serum levels where possible to indicate the physical effects of non-adherence; emphasizing the necessity of medication use as prescribed and the consequential benefits on health outcomes.

Both interview and focus group data was collected which strengthen the transferability and validity of findings, as what people said in a one-to-one interview settings was the same as a group setting. However, the findings may be limited as participants were all from one geographical location and of one cultural group (white British), so findings may not be generalizable to other geographical and cultural areas. Further work should explore the experience of adherence across cultural contexts in different disease states.

7 | CONCLUSION


The aim of this study was to explore the lived experience of medication adherence in patients with symptomatic and asymptomatic diseases. Medication adherence was an expected and routine part of everyday life in the 21st century for patients with both symptomatic and asymptomatic diseases, with the necessity to use medications

based on 'the system' of healthcare professionals, friends and family that supported medication use. Participants in this study reported medication non-adherence had negative social consequences, rather than negative health outcomes, and that these experiences were normalized by healthcare professionals. Further work is needed to validate and generalize these findings, as medication non-adherence has considerable negative impacts on health and well-being which may be being undermined. Healthcare professionals must carefully consider their role in normalizing episodic short-term non-adherence and highlight the important positive health outcomes of medication adherence.

CONFLICT OF INTEREST

None of the authors report any conflict of interest.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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